

A Decision-Making Model for Bioethical Issues

37

Introduction to Bioethics

Since the middle of the 20th century, rapid improvements in technology have changed the practice of medicine profoundly. The technology often allows physicians to restore or supplant basic bodily functions. Mechanical ventilators, heart pacemakers, kidney dialysis machines, exotic drugs, organ transplantation, and artificial nutrition and hydration are some of the life-extending tools available to the modern practitioner.

Initially, the use of these techniques was seen as altogether positive, a must-do choice for the physician. It was not long, however, before difficult questions surfaced. Just because we *can* maintain a person with artificial ventilation and nutrition, *should* we? Who should answer such a question: the patient, physician, family, nurse, social worker, hospital administrator, insurance company, ethicist, or politician?

Since the 1960s, questions like this one have provided us with an entirely new discipline or, more accurately, interdisciplinary: bioethics. Bioethics, or biomedical ethics, has become an immensely important topic. Few major hospitals are without an ethics committee to assist patients or health care providers when they need help. Colleges offer courses of study in medical humanities or bioethics. High school students, too, must be aware of the questions bioethicists study.

Paralleling the medical developments described above were striking advances in our understanding of genetics and molecular biology. Genetic knowledge has only recently been applied to specific diseases or patients, but the ethical questions that plague us about any medical technology apply also to medical biotechnology.

How do we decide what is right or wrong, what is better or worse, as medical biotechnology offers us ever more choices? Should everyone be screened to determine who the carriers of recessive alleles for genetic diseases are? Should genetically engineered

products be available to everyone, or should we sometimes screen requests for them (such as requests for human growth hormone)? Who should (and who actually will) have access to a person's DNA fingerprint? Are we on the road to employment and insurance discrimination based on genetic profiles? These are but a few of the ethical questions that can be posed.

Case Studies in Bioethics

Experience has demonstrated that while classroom discussions of bioethical questions are usually provocative and consciousness-raising, they often result in nothing more than sharing of emotional opinions about what should or should not be done. One effective way to get students to evaluate ethical issues objectively is to use case studies and a structured method of analyzing each case. In the approach we present below, students are presented with specific cases that pose not just ethical issues but also ethical dilemmas. Students identify an aspect of the case that represents an ethical dilemma and then apply ethical principles in a systematic way, following the decision-making model, to formulate a suggested solution. Students are required to justify the decisions they make about the case by citing authoritative documents such as the Nuremberg Code or the Hippocratic Oath, two widely used documents that set forth standards of conduct for biomedical professionals.

How to identify a dilemma

Not every bioethical case study presents a dilemma; many times, the possible courses of action are clearly right or wrong. A dilemma exists when there is no "right" course of action in a certain situation but, instead, several options, none of which is wholly acceptable. Ethical dilemmas revolve around trying to find the best solution when no solution is completely good. Students must identify the dilemma they will address and then propose a course of action that is based on adherence to basic ethical principles. The following example may clarify what does and does not constitute a dilemma.



Assume that a patient with a certain condition would be an appropriate candidate for a drug research study. The patient's physician places her on this drug without getting her permission. This situation is not a dilemma. It is just plain wrong. Even if the doctor believes the drug will benefit the patient, by all modern medical standards, the physician has the obligation to get the patient's informed consent to include her in the study. (The Nuremberg Code and the Declaration of Helsinki specifically address the ethics of research using human beings.)

On the other hand, assume that the patient has been given all the information she needs to make a decision. She is told that the drug has the potential to help her but might also have harmful side effects. She sees benefits and costs regardless of which decision she makes. Now we have a dilemma. A dilemma exists when no choice is ideal but all options have benefits and risks that must be carefully assessed.

Once a dilemma has been identified, the next step is to pose the dilemma in the form of a question. Often, more than one question can be formulated. By working through one question at a time, everyone in the group can be sure that everyone else is talking about the same problem. It is also helpful to categorize the issue being discussed. In the example given previously, the issue might be human research, and the question posed could be, "Should the patient agree to be part of the study or not?"

Basic ethical principles

To make ethical decisions, we must agree on some basic guidelines about what constitutes moral conduct. In the field of biomedical ethics, certain guides are well established. The moral-action guides or principles can be divided into four major principles and several secondary ones. These principles are listed below (the terms in parentheses are those used in bioethical literature). Before simply listing these for your students, you may want to have the students list guidelines for behavior and decision making that are important to them. Most values can then be categorized into one of the general principles listed here.

Major Ethical Principles

1. Do not harm (nonmaleficence).
2. Do good (beneficence).
3. Do not violate individual freedom (autonomy).
4. Be fair (justice).

Secondary Ethical Principles

1. Tell the truth (truth telling).
2. Keep your promise (fidelity and promise keeping).
3. Respect confidences (confidentiality).

4. Use the principle of proportionality: risk-benefit ratio (how much harm can be justifiably risked to effect good).
5. Attempt to avoid undesirable exceptions, also known as the wedge principle, the slippery slope, or the camel's nose.

Although these rules are simple, they represent fundamental values associated with respect for human dignity that most people agree to. These are the principles to which students should refer when making and justifying their decisions.

Using the Decision-Making Model

When faced with an ethical dilemma, how do we decide what to do, since there are no right answers? To assist students in learning how to follow a rational decision-making process based on ethical principles, you must provide a highly structured methodology. We suggest the decision-making model described below. Following the prescribed, step-by-step procedure laid out in the model greatly reduces the chance of getting off track. The model requires students to stay focused on the issue at hand and helps them develop critical-thinking skills.

Basic steps in the model, starting from a case study

1. Identify the question you want to address. Usually, for any given case, many questions could be considered. Choose the one you want to explore.
2. Identify the issue you are exploring (e.g., genetic screening, confidentiality, gene therapy, human research subjects). Naming the issue will help in the search for relevant literature.
3. State the facts in the case. Be sure to avoid inferences.
4. Think of as many possible decisions in the case as you can.
5. Gather additional information as needed.
6. Pick the decision you want to support.
7. State the ethical principle that supports your decision (your claim).
8. Identify an authority that supports your decision. Quote the authority, if possible.
9. Formulate a rebuttal. Under what circumstances would you abandon your claim?
10. How strongly do you believe your claim? What is your level of confidence, the qualifier?
11. "Box up" the case for reporting your decision.
12. Write a prose argument describing the case and your decision.

Two examples using this decision-making model are presented below. The first example is a typical school

ethics dilemma, and the second is a case from medical ethics. Different teachers may find one or both effective in demonstrating the model.

Rules for classroom discussion

Since the issues discussed in bioethics are controversial, it is important that rules of etiquette be observed from the very beginning. The following list has proved effective in the classroom.

1. Only one person at a time speaks after being recognized by the discussion leader.
2. Treat each other with respect; no name calling. Critique the argument, not the author of the argument.
3. Seek clarity by asking questions.
4. Look for gaps in the data.
5. Recognize your own biases.
6. Be true to your own position; do not jump on the bandwagon.
7. Keep emotions in check; use logic.
8. Do not follow authority blindly (the teacher doesn't know everything).
9. You must have a reason, not just an opinion. You can like pepperoni pizza better than anchovy pizza with no reason. You cannot decide bioethical issues based on opinions.
10. Be open minded and willing to be perplexed.

The case studies and "right" answers

In the two example cases that follow, as well as in several of the additional case studies, sample work-ups and decisions have been supplied to the teacher. These are included to show you how to use the model, not because they are the right answers. Remember that a dilemma is a dilemma because there is no perfect solution. The sample solutions may seem to be good resolutions of the situations, but it is critical to remember that your task as teacher is not to guide students to these particular resolutions or even to focus on the same questions. Rather, your task is to guide students to their own resolutions through use of the model.

For example, an alternative decision for case study 1 (Frank and Martin) would be for Martin to report what he saw to the judiciary council. If Frank is not guilty of cheating, he can explain himself to the council. The principles supporting this decision would be justice (being fair in that Martin is adhering to the agreed-upon Honor Code) and truth telling.

To avoid creating the impression that there are "right" questions to focus on and "right" answers, the sample solutions are not provided in the student pages.

Example: Case Study 1: Frank and Martin

This case shows an ethical dilemma but does not involve medicine or biotechnology. The case may be useful in introducing students to the method because it involves territory and issues that are very familiar to them. In addition, it serves as a useful example of how the decision-making model can be applied to many problems outside the bioethics arena.

Frank is an 11th-grade student at a small public high school that prides itself on its family atmosphere and strong academic reputation. The school has an honor code. Each student agrees to abide by a published list of rules. One part of the code obligates students to report observations of fellow students who may be cheating. A judiciary council composed primarily of students decide what should happen in each case. Frank works hard at school. He has a B+ average and hopes to go to a good college. He also works part-time, runs track, and helps at home with two younger brothers. Both of his parents work. Frank is a close friend of Martin. Martin is very bright and does well in school, although he does not have to put in as much time studying as Frank does. Martin does not have many extracurricular activities or responsibilities. During a history test, Martin notices that Frank appears to be cheating off a note card.

1. Identify the question

Often there are many questions. In this case, some might be as follows.

1. Should Martin report his observation to the judiciary council?
2. Should Martin tell Frank what he saw?
3. Should Frank report himself to the judiciary council?
4. Should other students be asked what they saw?

Other questions could be posed. It is important to encourage students to ask as many questions as possible. List them all, but finally choose one question for the group to focus on first. As students become more adept at using the model, they can be divided into small groups, with each group addressing a different question.

At the beginning, it is better to start with the same question. Working as a large group the first few times is also helpful in modeling the kinds of behaviors you want to encourage. Next, break up into small groups, but work on different questions. Eventually, work in small groups on different cases. To demonstrate the model using this case, we will use question number 1: should Martin report what he saw to the judiciary council?



II. Identify the issue

What general problem does the case demonstrate? In this case, we might say cheating or school rules. This step is an attempt to categorize the case.

III. State the facts of the case

What are the facts in the case? It is important to help students differentiate between facts and inferences. This skill is one that students may already have been introduced to in the laboratory, when they tried to draw conclusions based on data collected rather than on inferences. Many students will make unsupported assumptions or jump to conclusions. There are "rights" and "wrongs" at this step of the decision-making model.

In this case, for instance, we are not positive that Frank's note card is actually a cheat sheet. There is a possibility, perhaps remote, that Frank was working on another assignment and had permission to use the card. Students might also propose that everyone cheats and ask why Frank should get punished when others don't. That may or may not be true at this particular school. Nor can we make assumptions about Frank and Martin's friendship. Maybe they had a fight and Martin just wants to get Frank in trouble. It is a possibility but not a fact in this case. Time spent discussing the facts is worthwhile, since it can prevent confusion later in the discussions.

Once the facts have been established, it is helpful to list them in an accurate but concise manner. Facts must be true, relevant, and sufficient.

- Frank was seen using a note card; the honor code requires Martin to report the incident.
- Frank is in 11th grade, works, is a B+ student, and runs track.
- The school is small, with a good reputation.
- Frank plans to go to college.
- Martin does well in school with less effort than Frank.
- Martin does not have many extracurricular activities.

(The relevance of the last three facts is worth discussing.)

IV. List as many possible decisions as you can

What are the possible answers to the question of whether Martin should report what he saw? Encourage students to generate as many choices as possible. List them all. Promote creative and lateral thinking by

asking leading questions and allowing adequate wait time. Here are some possible choices.

1. No, Martin should not report what he saw. It could harm Frank. Maybe Frank had permission to use the card. How does Martin know whether Frank was really cheating?
2. Yes, Martin should report what he saw. It is his duty under the code. He breaks his own promise to abide by the code if he does not tell. Frank may need help if he did indeed cheat. If he didn't cheat, he can explain to the council.
3. Martin should tell Frank's parents and let them decide what to do.
4. Martin should tell his own parents and let them decide what to do.
5. Martin should tell another student and let the other student decide what to do.
6. Martin should tell Frank what he saw and give Frank the opportunity to tell the judiciary council what happened. If Frank refuses to go to the judiciary council, then Martin should tell.

V. Gather additional information as needed

It is absolutely critical that students learn to seek relevant information and not to make decisions based on uninformed opinion. At the very least, students should recognize when there are gaps in the information they have. This sample case probably will not require gathering additional background information. However, other cases may. For example, to weigh the risks and benefits in a case involving use of an experimental drug to treat a patient, students may want to know just how severe the patient's disease is. It might also be appropriate for them to find out what sort of safety testing a drug must undergo before it is approved for experimental treatment of humans.

VI. Pick the decision you wish to support

We have presented six possible decisions (your class may generate many more). Encourage solutions that represent compromise. Since ethical problems are usually complex, it is important to take time for thoughtful, honest reflection. The students must have a reason for the option they choose, and that reason should be related to one of the principles listed earlier in this chapter. However, students may make different decisions based on different principles.

For our example, we will choose option 6. With this choice, we respect Martin's obligation to tell what he

saw, but at the same time, we might be able to avoid harming Frank.

VII. Identify the ethical principle that supports your decision

An ethically justifiable decision can be based on alternative principles. In a dilemma, adherence to one principle often results in the breach of another; dilemmas exist because principles often conflict. Application of different basic values can lead to different responses to a situation.

Students should learn what the basic principles are and recognize how they can be applied. One of the goals of using this model in the classroom is for students to develop an appreciation for the fact that two responsible, moral people can make very different decisions in a case because they are guided by two different basic principles.

The logic involved in the choice of principle(s) for these classroom cases should be explicitly discussed and/or written about by the students. They need to be able to justify why they have chosen one principle and why they are willing to breach the alternative principle(s). Although students can choose more than one principle to support their decision, it is helpful to force them to choose only one at the beginning to be certain they understand the differences between principles. In the sample case, the first principle we are adhering to is avoiding harm and the second is truth telling.

VIII. Identify a supporting authority

What experts or authorities would back up our position on this case? Normally, we would look to professional codes of ethics. In this case, the honor code itself would be the authority. In bioethical decisions, several codes of ethics are used; these codes include the Hippocratic Oath, the American Medical Association Code of Ethics, the American Hospital Association's Bill of Rights for Patients, and the American Nursing Association Code of Ethics as well as the Nuremberg and Helsinki statements. Depending on the time available, library research is always desirable. Have your students find these documents in books and bring them to class.

IX. Formulate a rebuttal

Under what circumstances would we change our decision about what to do? Here again, it is important to encourage students to think creatively. This section is often difficult, because students are invested in their

choice and may not be able to imagine a circumstance that would make them change. In this case, what if Frank were taking a different test, perhaps a more advanced one, and had permission to have the note card? What if the note card was actually an appointment slip that Frank was checking to be sure he was on time for an after-school doctor's appointment? If Martin knew that kind of information, then surely the problem would evaporate.

X. State your level of confidence in your decision

The student should formulate a one- or two-word statement to describe how strongly he or she believes his or her own argument. Until they have more experience, students tend to believe their own arguments are infallible. One way to assess the strength of the argument is to gauge the likelihood of rebuttal. If a rebuttal is highly unlikely and the rest of the argument makes sense, then the argument is a strong one. Also, if the principle ties the claim and the facts tightly together, then the argument is strong. Forcing students to qualify their arguments is one way to promote self-evaluation. As students work up more and more cases, they become better at constructing an argument and more realistic about its strength. Qualifiers might be "moderately confident," "absolutely confident," or "questionably confident." In this case, we will use "strongly confident."

XI. Box up the case for reporting

See Figure 37.1 for a "box" of the sample case. Obviously, many other boxes could have been constructed. Students, usually working in groups of three or four, transfer this box to a transparency and present their case to the class, starting with the facts. Having students critique one another's arguments is a valuable lesson as well.

XII. Prepare a prose argument

Finally, if time permits, students can write up their arguments, using the box as an outline. They should produce a paper that can be understood by someone unfamiliar with the original case. Students who write well have little difficulty with this task. However, many need help using proper transitions. They should also explain more in the paper than the box can show. For instance, why is avoiding harm more important, at least initially, than telling the truth immediately? Students who are willing to apply this model to other classes often find it works very well in writing papers in English or history class. This reasoning model can be applied to almost any discipline.



Issue:

Cheating

Question:

Should Martin report what he saw to the council?

Facts

- Frank seen using note card during test
- Honor code requires Martin to report incident.
- Frank in 11th grade, works, B+ student, runs track
- Small school with good reputation
- Frank plans to go to college.
- Martin does well in school.
- Martin has few extracurricular activities.

Authority

School honor code

Qualifier

Strongly confident

Principle

1. Do no harm.
2. Tell the truth.

Decision

Martin should tell Frank what he saw and give Frank the opportunity to tell the judiciary council.

If Frank refuses to go to the council, Martin should tell the council himself.

Rebuttal

If Martin learns that Frank had permission to use the card or that the card had nothing to do with the class, then there is no need to report the incident.



Social Issues

Figure 37.1 "Box" of example case study 1: Frank and Martin.

1. Mr. Johnson should remain on the ventilator.
2. Assuming Mr. Johnson is competent, discuss the situation with him. If he directs the doctor to remove the ventilator, then remove it. Keep him clean and comfortable, and treat him with dignity, but do not employ heroic measures. If he wishes to be left on the ventilator, continue the present course.
3. If Mr. Johnson cannot communicate or is deemed to be incompetent or both, Mrs. Johnson, the attending physician, nurses, social workers, etc., should decide what Mr. Johnson would direct were he competent and able to communicate.
4. Assuming that Mrs. Johnson's position is corroborated (that Mr. Johnson would not want life support), then Mr. Johnson's ventilator should be removed as in option 2.

V. Gather needed background facts

Obviously, no further information about the Johnsons is available, but students will probably need to find out more about emphysema to understand Mr. Johnson's situation. They also may wish to learn more about breathing machines and their uses.

VI. Make a decision

For the purpose of this example, we will choose decision 2: if Mr. Johnson directs the doctor to remove the ventilator, then remove it, but keep him clean and comfortable, and treat him with dignity. Do not employ heroic measures.

VII. Identify the guiding principle

Since making the decision involves asking Mr. Johnson what he wants, the decision is based primarily on respect for his autonomy. We are trying to let him decide for himself what he does or does not want. At the same time, we are trying to avoid harming him. Some would argue very convincingly, however, that removing him from the ventilator will result in his death, which is the ultimate harm. Others will argue that the ventilator is merely prolonging the moment of death and that in this situation, although removing the ventilator may hasten Mr. Johnson's death, that is not a harm. Herein lies the crux of these deci-

sions. What principles do the individual students think are most important in each case? They need to be able to say why they think one principle takes precedence over another.

VIII. Cite a supporting authority

As time permits, students can read about similar cases, and they should examine the codes of ethics mentioned in the first sample case.

IX. Formulate a rebuttal

Under what circumstances would we abandon our decision? For instance, if Mr. Johnson is not competent and no one can corroborate that he did not want life support measures, then we may decide to leave him on the ventilator. Perhaps we discover that Mr. and Mrs. Johnson were having marital problems but that Mr. Johnson still has a \$5 million insurance policy with Mrs. Johnson as the beneficiary. If he cannot speak for himself, we may be reluctant to discontinue the ventilator.

X. State your level of confidence

This case has quite a few unknowns, so we may not be very confident about our decision. We don't know whether Mr. Johnson is competent; we don't know what his prognosis is without the ventilator; we don't know how he felt about his quality of life before this episode. There are enough questions to make us somewhat unsure about our decision.

XI. Box

A box for this case is shown in Figure 37.2.

XII. Prose argument

As time and interest dictate, students can write up their arguments in paragraph form.

In the next two chapters, the decision-making model will be applied to gene therapy and genetic screening cases. Blank "box-up" forms for those exercises are provided in Appendix A.

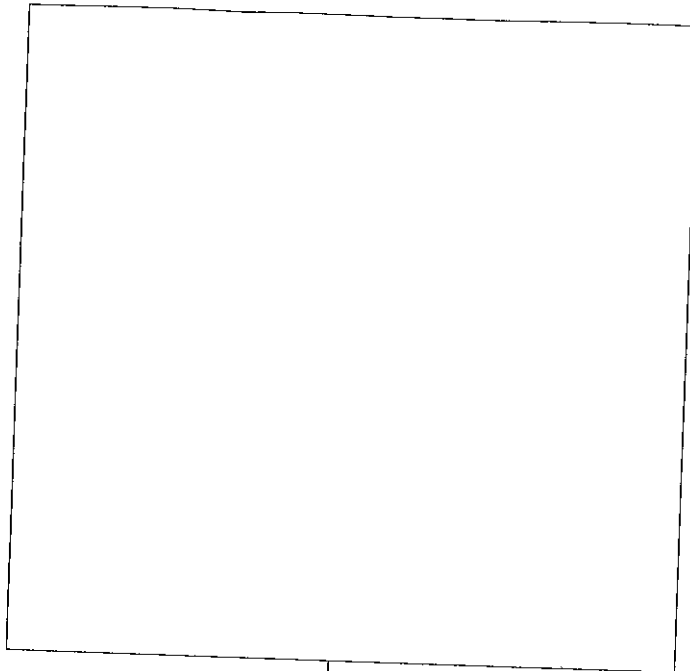


"Box-up" forms for A Decision-Making Model for Bioethical Issues

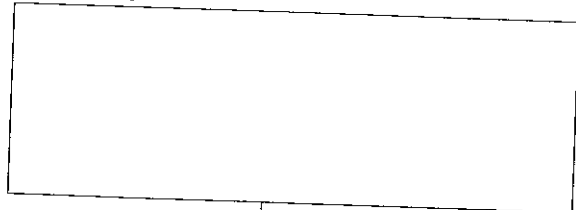
Issue:

Question:

Facts



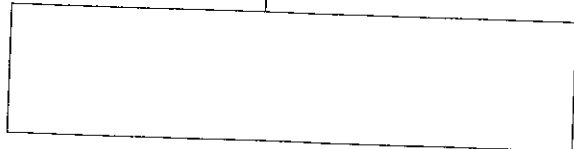
Authority



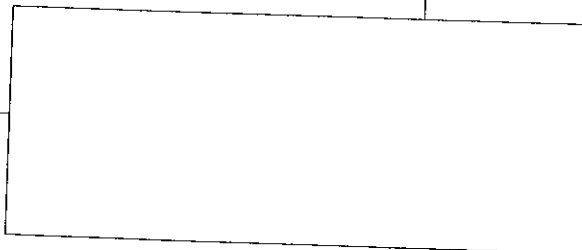
Qualifier



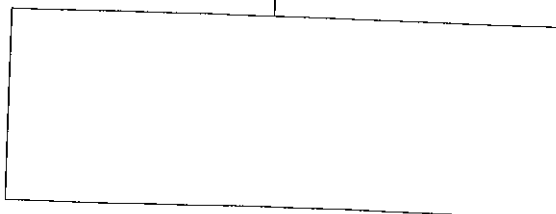
Principle



Decision



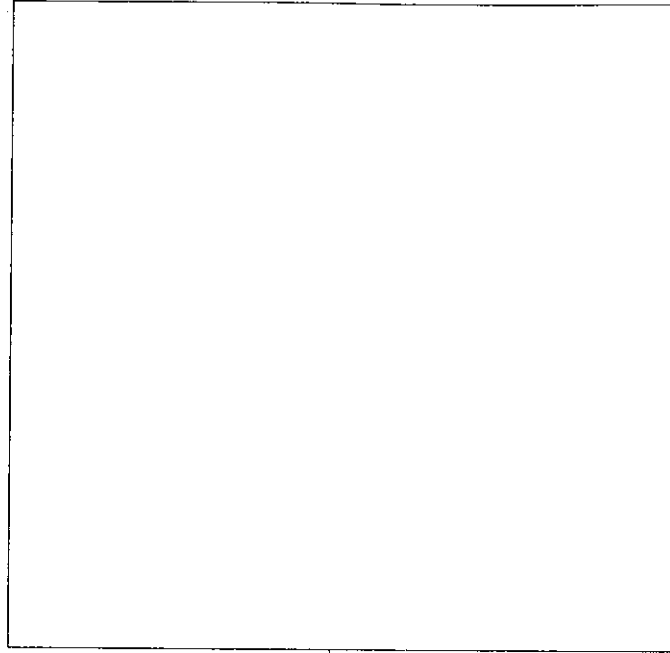
Rebuttal



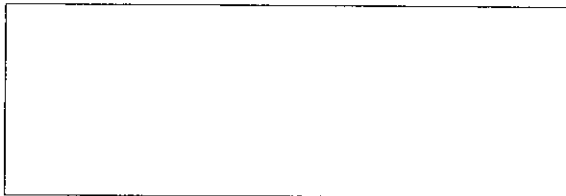
Issue:

Question:

Facts



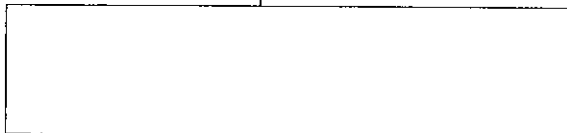
Authority



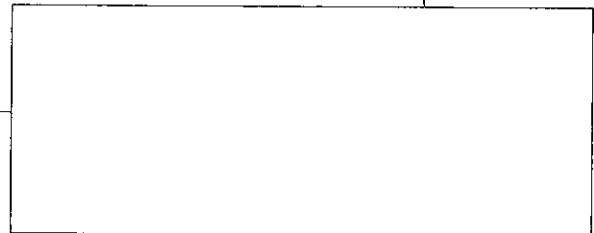
Qualifier



Principle



Decision



Rebuttal

